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# EXPERTS BY EXPERIENCE IN MENTAL HEALTH NURSING EDUCATION: WHAT HAVE WE LEARNED FROM THE COMMUNE PROJECT?

**Running title: Experts by Experience in mental health nursing education**

## **Authors:**

Professor Brenda Happell

RN, Cert Psych Nurs, BA (Hons), Dip Ed, B Ed, M Ed, PhD, FACMHN

School of Nursing and Midwifery

Faculty of Health and Medicine, and

Hunter Institute of Medical Research, and

Priority Centre for Health Behaviour

University of Newcastle

University Drive

Callaghan

New South Wales, 2308

Australia

Brenda.happell@newcastle.edu.au

Orcid ID: 0000-0002-7293-6583

Dr Aine Horgan,

PhD, MSc, BNS, PGCert T&L, RPN,

Senior Lecturer,

School of Nursing and Midwifery,

ENGAGE: Interdisciplinary Clinical Mental health Research Network

University College Cork,

Cork,

Ireland

aine.horgan@ucc.ie

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ORCID: 0000-0001-6377-4140

Ms Fionnuala Manning

Expert by Experience lecturer,  
School of Nursing and Midwifery,  
University College Cork,  
Cork,  
Ireland

fionnualamanning@hotmail.com

Mr Rory Doody,

B. Soc. Sc. (Hons),  
Area Lead for Mental Health Engagement,  
Southern Area Health Service Executive,

Expert by Experience lecturer,  
School of Nursing and Midwifery,  
ENGAGE: Interdisciplinary Clinical Mental health Research Network  
University College Cork,  
Cork,

Rory.Doody@hse.ie

Ireland

Ms Sonya Greaney

Dip SPH, PG Cert Peer Support  
Peer Support Worker,  
Southern Area Mental Health Services,

Expert by Experience lecturer,  
School of Nursing and Midwifery,  
University College Cork,  
Cork,

Ireland,  
sonyag1@live.com

John Goodwin,  
MA, PGDip, Bsc (Hons), BA (Hons), ALCM, Dip Mgmt, RPN  
Lecturer,  
School of Nursing and Midwifery,  
ENGAGE: Interdisciplinary Clinical Mental health Research Network  
University College Cork,  
Ireland,  
ORCID ID: 0000-0002-2044-1861  
John.Goodwin@ucc.ie

Ms Julia Bocking  
B Phil (Hons), B Soc & Comm Stud (Community Development),  
PhD candidate  
ANU Medical School,  
College of Health and Medicine,  
The Australian National University,  
Woden  
Canberra,  
Australia  
Julia.bocking@anu.edu.au

Ms Shifra Waks  
BA (Hons), MIHP, B Int and Global Stud  
Consumer Research Assistant  
School of Nursing and Midwifery  
University of Newcastle  
University Drive

Callaghan  
New South Wales, 2308  
Australia  
Shifrawaks1@gmail.com

Elisabeth Hals,  
MA,  
Assistant Professor, Expert by Experience  
Faculty of Health and Social Sciences,  
Inland Norway University of Applied Sciences,  
Hedmark,  
Norway  
elisabeth.hals@inn.no

Martha Griffin,  
H. Dip in Community and Youth Work  
Expert by Experience Lecturer in Mental Health,  
School of Nursing & Human Sciences, Dublin City University.  
Dublin  
Ireland  
Martha.griffin@dcu.ie

Dr Brett Scholz  
BHSci (Hons), PhD  
Research Fellow  
ANU Medical School,  
College of Health and Medicine,  
The Australian National University,  
Woden  
Canberra,

Australia

Brett.Scholz@anu.edu.au

Orcid ID: [orcid.org/0000-0003-2819-994X](https://orcid.org/0000-0003-2819-994X)

Arild Granerud,

PhD,

Professor

Faculty of Health and Social Sciences,

Inland Norway University of Applied Sciences,

Hedmark,

Norway

[arild.granerud@inn.no](mailto:arild.granerud@inn.no)

PROFESSOR BRENDA HAPPELL (Orcid ID : 0000-0002-7293-6583)

DR BRETT SCHOLZ (Orcid ID : 0000-0003-2819-994X)

DR MARI LAHTI (Orcid ID : 0000-0002-3403-5418)

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## **EXPERTS BY EXPERIENCE IN MENTAL HEALTH NURSING EDUCATION: WHAT HAVE WE LEARNED FROM THE COMMUNE PROJECT?**

The COMMUNE (co-produced mental health nursing education) was an international project established to embed EBE perspectives in mental health nursing education by developing and delivering a specific mental health nursing module. The underlying intention of this project was to go well beyond ad hoc implementation and tokenistic approaches to EBE involvement. Standards for co-production of Education (Mental Health Nursing) (SCo-PE [MHN]) was developed to provide guidance to the increasing number of academics seeking genuine and meaningful involvement of Experts by Experience in the education of health professionals. These standards were recently published in the Journal of Mental Health and Psychiatric Nursing (Horgan et al., 2020): <https://onlinelibrary.wiley.com/doi/abs/10.1111/jpm.12605> and prompted this Editorial to discuss the COMMUNE project more fully, including the lessons learned.

Changes to mental health service delivery have been exponential, resulting in significant implications for practitioners. We continually hear the call for increased focus on recovery-oriented practice, amidst a growing expectation that service users be recognised and supported as active



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participants in services, at both the individual and systemic levels. At the same time, we are challenged by reports of inadequate care, a continuing reliance on coercive practices and tokenistic responses to service user participation. These changes require a significant paradigm shift from the traditional medical model approach to care and treatment. The urgent need for a nursing workforce with the skills, knowledge and attitudes to provide professional leadership in navigating the changing landscape presents challenges of its own. The difficulty in attracting sufficient people into mental health nursing is continually noted, particularly in countries with a generic approach to nursing education. As is often the case, the challenges receive considerably more attention than the strategies and solutions that might change the situation.

Nursing education is integral to influencing nurses of the future to develop the skills, knowledge and attitudes needed to truly 'commune' with service users. Despite this, nursing programs in many countries still tend to focus heavily on bio-medical approaches to mental health care. Strong emphasis is placed on teaching symptoms and diagnosis, with nursing practice and skills often directly emanating from this paradigm.

Recovery-orientated approaches to practice are generally taught by well-intentioned clinical academics who believe in its importance in transforming practice. While it may be argued that any teaching of recovery is better than none at all, doing so does not acknowledge that recovery was developed by the service user movement in direct response to the dehumanising impact of the medical model. Recovery being taught by anyone other than service users is at clear odds with its underlying philosophy and intentions.

Involving service users (referred to here on in as Experts by Experience [EBE]) in the education of nurses and other health professionals, which decades ago would have seemed impossible, is now gaining traction and pockets of activity are evident. Nevertheless, this involvement generally remains ad hoc, minimal, and often directed by the broader curriculum, primarily developed by nurses and designed to produce the kind of graduates that nurse academics believe they should be.

Co-production was fundamental to this project; the team included EBE and mental health nurse academics in as close to even numbers as possible and practicable. The process was extensive, collaborative and innovative. To garner the lived experience perspective on mental health nursing as broadly as possible, the first step was to conduct focus groups with service users from each country (Horgan et al., 2018). The full team of 12 EBE and 10 mental health nurse academics spent a week in Iceland co-producing the learning module. A whole-group, paper-based consensus building exercise was undertaken. After initial consideration of the main themes from the focus group data, EBE and nurses worked in small groups to identify and record key items. The full group reformed and began combining the ideas. Some ideas were unanimously supported, while others required discussion and refinement before being accepted by the team. Following a lively and robust exchange, the group decided on specific principles to underpin the learning module, providing sufficient structure while allowing individual autonomy for each EBE.

The consensus building exercise was a pivotal moment in the COMMUNE project. It provided a communicative space for diverse expertise and perspectives to come together, focused on a common purpose that recognised and respected the unique contribution each individual made. The outcome was a set of principles that guided development of the content,

learning outcomes and relevant infrastructure to deliver this exciting module to undergraduate nursing students. The module was either led or delivered solely by EBE (Horgan et al., 2020).

Contributing to the evidence base for EBE-led mental health education was a key aim of this project. To this end, a mixed method evaluation was conducted pre and post module delivery. Methods included surveys administered before and after delivery of the learning module to measure students' attitudes to people diagnosed with mental illness, anxiety towards and sense of preparedness for working in the mental health field, attitudes towards mental health nursing as a career, and attitudes to service user participation and recovery. After completing the module, students expressed more positive and improved attitudes towards people labelled with mental illness, particularly where student attitudes were notably more negative at baseline (Happell, Platania-Phung, et al., 2019).

Focus groups with nursing students and individual interviews with EBE involved in the learning module were held to gain more detailed understandings of individual experiences. Findings from student interviews suggest the experience was profound. Participants described how being taught by EBE had completely altered their previously held views of mental illness and mental health nursing. Students described and demonstrated an understanding of *the person behind the diagnosis* (Happell, Waks, Bocking, Horgan, Manning, et al., 2019). Through that new lens, they appreciated the importance of recovery-focused practice and a holistic approach to working with people experiencing mental distress (Happell, Waks, Bocking, Horgan, Greaney, et al., 2019). These findings are vital given the stereotypical and stigmatising attitudes that students often bring to their nursing education. These concepts are difficult to grasp theoretically and finding a way this can be achieved is very exciting.

Interviews with EBE supported many of these findings, and they observed significant differences in students' development throughout the module. *Seeing the person behind the diagnosis*, was a prominent theme of the analysis (Bocking et al., 2019). EBE observed students developing a stronger understanding of recovery, with EBE themselves as role models for recovery. Despite some identified barriers, EBE found the experience rewarding and satisfying. In most instances EBE felt supported by their nursing colleagues although it was a very steep learning curve for all. This was not universally the case, in one university, nursing teaching staff (not part of the COMMUNE project) displayed overtly stigmatising attitudes to the EBE. Pressure was frequently applied to modify EBE content and delivery to try to achieve more uniform content with the clinical offerings (Happell, Bocking, Scholz, & Platania-Phung, 2019). Clearly they did not respect and acknowledge the importance the unique knowledge the EBE brought. While there is much to be encouraged from the COMMUNE findings, it is very important that implementation of EBE roles involves preparing and educating the nurse academics who will work closely with EBE.

Coproduction was front and centre through this entire project – not that we always got it right. For some less familiar with working with EBE, it was a very steep learning curve. Similarly, there was much to be learned by EBE who had not previously engaged in this kind of work. One of the greatest challenges in co-production is respecting the expertise gained from being labelled with a mental illness, and mental health service use.

As a term, 'coproduction' is often used to describe service user involvement that falls significantly short of the principles that apply to this level of collaboration, for example being a member of an advisory committee, or a

brief 'teaching' engagement (often comprising the telling of personal stories). Such involvement is not coproduction; it is tokenism.

Importantly, we have acknowledged our shortfalls and limitations. EBE are rarely in positions equivalent to those of nursing team members. Once funding is received, there is capacity to pay EBE. Unfortunately, this does not help when preparing applications for funding. Most EBE in this project were not in paid positions, and therefore their contribution was largely voluntary. This poses a major inequity which means either the expertise and contribution of EBE is not recognised through remuneration, or they are unable to contribute at all. It would have enhanced the project to have the EBE as equal partners in the application stage.

While EBE were paid to deliver the learning module and to attend core project meetings, at the conclusion of COMMUNE, most were no longer in paid positions. This meant that for much of the work in preparing conference presentations and articles for publication, we were again relying on voluntary time. EBE did not have access to the same levels of funding to support conference attendance and further promote the outcomes they contributed to so appreciably. To overcome these barriers we need EBE in funded academic positions within nursing schools (and indeed other health disciplines). This will allow them the scope to contribute to teaching, research and other scholarly activities, and to apply their expertise while enjoying the resources provided in academic environments. Indeed, when lived experience is truly valued in partnerships, benefits are maximised for all parties (Scholz, Bocking, & Happell, 2018).

The COMMUNE team are proud of the process and outcomes of this project. Our findings support the broader research literature in demonstrating

the value of EBE to mental health nursing education. The robust research evaluation adds to the limited body of knowledge in this area. The international nature of the project (Europe and Australia) extends the reach of our findings to countries and universities at different stages of developing EBE led teaching and learning.

Practice Guidelines were developed as an outcome of the COMMUNE project, to provide a more comprehensive overview of our experiences, learnings, limitations and barriers. The Guidelines and further information about the project can be found at the website: <https://commune.hi.is/>. Hopefully, the Practice Guidelines will be useful for those who intend to co-produce learning programs or modules in mental health nursing.

The COMMUNE team believes EBE are integral to quality nursing education, and the developing evidence base clearly supports our views. Nursing has already shown leadership in this space, the time to push this further and consider EBE academic positions as core is now. We issue the challenge to you all.

The COMMUNE team

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